

White House Conference on Aging

Post-Event Summary Report

Name of Event: Empowering Family Caregivers Sessions I & II
Washington County Longevity Forum:
The Aging Dilemma in a Rapidly Changing Environment

Date of the Event: July 28, 2005

Location of Event: Western Maryland Hospital Center
1500 Pennsylvania Avenue
Hagerstown, MD 21742

Number of Persons Attending: Session I - 12 attendees
Session II - 5 attendees

Sponsoring Organizations: Western Maryland Hospital Center
Washington County Commission on Aging
Washington County Health Department
Washington County Department of Social Services
United Way of Washington County
Hospice of Washington County
Homewood at Williamsport
Alzheimer's Association, Greater Maryland Chapter
MIHI, Inc. (Many Individuals Helping Individuals
ElderSystems

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Please follow this format for each priority area, with the most important listed first. Please ensure that your organization's name and contact information is provided at the bottom of each page submitted.

Empowering Family Caregivers

Session I

(Not Ranked)

Priority **Issues** Identified by **Session I** Members:

1. Lack of Help or Resources
2. End of Life Issues: knowing the wishes / plans of loved one
3. Isolation of Caregiver enhanced in rural areas
4. Lack of Resources/Services in the Area
5. Lack of Caregiver planning
6. Do not know where to even begin to find resources

Priority **Barriers** Identified by **Session I** Members:

1. Under-funding and / or lack of funding
2. Employer flexibility toward Caregiver needs
3. Strong focus on curative versus palliative care
4. Barriers to independent living
5. Lack of services
6. All resources are not available or known
7. Funding

Priority **Solutions** Identified by **Session I** Members:

1. A combination of the following:
 - a. A demonstration project which incorporates,
 - i. Development and implement of a case management model
 - ii. Development and implement of a longevity resource center
 - iii. Advance care planning
2. One place where all services are available
3. Care manager for all recipients
4. Support Center
5. Respite Care

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Session II

(Not Ranked)

Priority Issues Identified by Session II Members:

1. Do not know where to start to find resources
2. Lack of resources/services in the area
3. Lack of planning for caregivers

Priority Barriers Identified by Session II Members:

1. All services not available or known by recipient of caregivers call, requires multiple calls on the part of the caregiver to identify and secure services
2. Lack of funding

Priority Solutions Identified by Session II Members:

1. One place where all services are available.
 - a. One stop shop:
 - i. Counseling
 - ii. Education
 - iii. Life person
2. Care management for all care recipients
3. Support Center

List of all issues raised Session I

Below are all ideas presented by the members of Session I Guided Brainstorming, which addressed issues, barriers and solutions to “Empowering Family Caregivers”.

Issues, Barriers & Solutions Identified:

Caregiver Issues:

- Burn Out
- Being recognized as the legitimate / legal guardian of the person with the disease.
- Who has expertise, not be acknowledged as knowledgeable
- Not asking for help
- Daughter or son become nurse and lose family relationship
- Not be reimbursed for lost time at work
- Caring for more than immediate family and lack of acceptance
- Sandwich Generation-Caring for Children and Parents
- Lack of help or resources
- Lack of respite care
- Lack of time and resources to see the “big picture”
- Lack of expanded support network such as community/Church/Family
- Lack of understanding how “system” works or what’s available
- Lack of Respite (caring for the caregiver)
- Caregiver neglects own health
- Income Differentials
- End of Life Issues-Know wishes, plan, give clout to wishes
- Isolation of caregivers enhanced in rural areas
- Help Caregiver be aware they are in a dilemma
- Look at resources and how best to access
- Develop a good case mgt. model + compensation
- Develop a Pilot Project-Solution
- Seeking help sooner-services help longer
- Simpler system to access e.g. invitation to access
- Use of internet to get info in hands of those in need
- Healthcare system disintegration, e.g. misdirection of healthcare professionals
- Role reversal
- Focus on curative vs. palliative
- Medicine management
- Lack of emotional care
- Mentoring

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Caregiver Issues Continued:

- Not being heard as the care giving voice. Not understanding the caregiver's need to know and to be listened to.
- Low pay for CNA and Nursing Assistants
- Health care system vs. Family presence in control of end of life issues
- Focus on curative vs. palliative
- Lack of compensation for doctors to spend needed time w/ patient
- Pain Management
- Patient advocate for self
- Family Member/ Loved Ones advocate and accepted
- Full disclosure: active dialog conversation: presentation of options, possible outcomes, with decisions made and carried out\
- Lack of understanding how "system" works or what's available
- Community issues with non English speaking cultures
- Develop a caring for the caregiver program
- Encourage caregiver to seek help sooner and continue use of services longer
- Seniors shy about asking for help

Provider's Issues:

- Not being heard as the care giving voice. Not understanding the caregiver's need to now and to be listened to.
- Low pay for CNA and Nursing Assistants
- Health care system versus family presence in control of end of life issues
- Focus on curative versus palliative care
- Lack of compensation for doctors to spend needed time with patient
- Pain management
- Patient advocate for self
- Family member/loved ones advocacy accepted
- Distortion of priority-Healthcare system disintegration
- Misdirection of healthcare professional priorities

Business/ Employer issues:

- Costs to caregiver and employer when employee has to take off work to perform caregiver tasks.
- Lack of employer understanding/flexibility
- Employer offer benefits-Eldercare
- Low pay for CNA and Nursing Assistants

Community Issues:

- Non traditional family structures
- Community issues with non English speaking cultures
- Explanation of Family Structure to include “chosen” family
- Lack of Knowledge of “true” family structure in area
- Population is living longer
- Town meeting to hear the Caregiver’s voice speaking to decision-makers
- Stigma attached to being a Caregiver
- Lack of identified Care giving issues
- Provide a “safe place” to go for help
- Lack of advanced care planning
- Lack of community system of care
- Lack of programs to care to for the caregiver
- Demonstration Project
- One place where all services are available
- Care manager for all recipients
- Support center
- Challenge of cultural diversity
- Faith based centers addressing discrimination issue
- Remodeling needed to accommodate needs

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Barriers Identified:

- Under-funding/lack of funding
- Isolation of care givers(Shut-in)
- Caregiver accepts their need for help
- Stigma attached to being a caregiver
- Ways and means to access help
- Health care system
- Insurance
- Income replacement when time off
- Employer flexibility, work offsite, flexible hours/shifts
- Lack of extended funds
- Caring for multiple “patients
- Lack of services
- Sibling issues-taking care of mom
- 80 year olds caring for 100 year olds and grand daughter
- Death of Caregiver-Leaving behind “patient
- Lack of respite care
- Transportation-car is only means
- Barriers to independent living
- Doorway size/Ramps
- Lack of social support
- Lack of community understanding support
- Under funding/lack of funding
- Employer flexibility
- Strong focus on curative vs. palliative care
- Barriers to independent living
- Lack of services
- All resources not available/know
- Funding

Solutions Identified:

- Care Management Model
- County Demonstration Project/Pilot
- One voice for caregivers
- Longevity Resource Center
- Creation of new entity
- Education of Legislators
- Advanced care plans: adopt one county-wide which is respected and followed
- Increase health-literacy
- Teach how to communicate clearly
- Demonstration project
- Develop new ways of for caring for elders
- Lack of help or resources
- End of life issues
- Knowing the wishes/plan of loved one
- Isolation of Caregiver enhanced in rural areas
- Lack of resources/services in area
- Community system of care
- Lack of caregivers planning
- Don't know where to start finding resources
- Use of internet to get information in hands of those in need
- Simpler system to access: invitation to access
- Develop a good case management plus compensation
- Legislative actions
- Develop a Pilot Project
- Help Caregiver be aware they are in a dilemma
- Look at resources and how best to access

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List of all issues raised Session II

Below are all ideas presented by the members of Session II Guided Brainstorming, which addressed issues, barriers and solutions to “Empowering Family Caregivers”.

Issues Identified:

- Do not know where to start to find resources
- Do not think of themselves as caregivers
- Only call for help when crisis or conflict
- Employers not supporting caregivers
- Caregivers burnout, where to go for help
- Person who needs care does not understand that caregiver also needs care
- Caregiver's hid their needs
- Educate on how to deal with it
- How to educate when caregiver providing care 24/7
- How to deal with difficult situations: Help from others, help with driving or stopping someone from driving, etc.
- Dealing with family dynamics
- Switching roles: daughter becomes caregiver
- Who cares for patient when caregiver dies?
- Educating caregiver on options
- One place to find services
- Educate provider on what services are available to them
- Implement 211
- Financial support / tax breaks
- Flexible work situation so caregiver does not loose their job
- Employer understand and support caregivers situation
- Sandwich generation
- Help with decision-making: finances, care, power of attorney
- Legal issues: POA, DNR (do not resuscitate)
- How to deal with personal care issues
- Care management
- One stop shop for legal and life issues
- Lack of resources/services in the area
- Continued growth of elder population
- Caregiver's commute: away long hours
- Lack of planning for caregivers

Issues Identified Continued:

- Caregivers do not know where to start
- Non education of potential future caregivers, present day caregivers, and patient
- HIPPA regulations prohibit inter-agency correspondence
- Money not enough to help families access community resources e. g. home health agencies
- Transportation help needed
- Physical strength of caregiver
- Age of caregiver
- Isolation of caregiver
- Location of caregiver
- Lack of a loan closet
- Depression/suicide: caregivers feels as though there is nothing to live for
- Advocacy: who does it, do not know how to, do not have time to advocate
- Legislators: If they are not a caregiver they do not understand the situation, need to be educated
- Legislators make decisions but do not know what they are basing their decisions on
- Who advocates for the caregiver
- Spiritual support
- Social isolation

Barriers Identified:

- Not reaching a “live” person when calling
- All services not available or known about in one area
- Funding
- Not finding correct information on programs
- Not enough time to do it all
- Lack of attention to aging population
- Social attitude toward senior population
- Lack of home environment to accommodate needs of patient
- Time constraints
- Lack of patience with patient
- Insurances: who takes what
- Loved ones’ resistance to care
- Transportation

- Health care
- Environment not conducive to care
- Denial
- Family issues: Who handles what and how do they work together
- Decision makers not seeing the full picture
- Caregiver not perceived as credible
- Caregiver pride
- Caregiver not knowing and/or wanting to air “dirty laundry”

Solutions Identified:

- One place where all services are available
- Care manager for all care recipients
- More social services
- Transportation: Affordable, public, free
- One Stop Shop: Counseling, education, life person
- Caregiving services mall
- Support Center
- Publicizing what is available
- Upfront education
- Respite Care